



Secretary Kathleen Sebelius  
US Department of Health and Human Services  
Hubert H. Humphrey Building  
200 Independence Avenue SW  
Washington, DC 20201

**VIA Electronic Submission**

March 30, 2012

Dear Secretary Sebelius:

Congratulations on the development of a thorough and thoughtful draft of the National Plan to Address Alzheimer's Disease (National Plan). The Partnership to Fight Chronic Disease appreciates the opportunity to comment on the draft and looks forward to seeing the final plan implemented. PFCD is a national coalition of patients, providers, community organizations, business and labor groups, and health policy experts committed to raising awareness of the number one cause of death, disability, and rising health care costs in the U.S.: chronic disease.

Alzheimer's Disease and related dementias (AD) presents a public health crisis in every sense and as such requires an unprecedented collaborative effort to address it effectively. A robust National Plan *and* the resources needed to implement it are required to assure we achieve, as the National Plan states, a "nation free of Alzheimer's Disease." To help support these efforts, we offer the following comments on the draft National Plan:

**Expanding Research to Prevent and Effectively Treat Alzheimer's Disease by 2025**

The National Plan includes a solid framework for enhancing research efforts to find ways to prevent and better treat AD. In discussions over research priorities for AD, we encourage consideration of ways to improve care management, care coordination, long-term care, and other aspects of the delivery of care for people with AD in addition to traditional clinical research efforts. For example, programs funded by the Centers for Medicare and Medicaid Innovation and similar demonstration efforts targeting delivery system reforms should include consideration of patient-centered care models for people with AD and ways to enhance coordination between inpatient and outpatient medical care, community-based services, and long-term care, including managing transitions of care between providers and care settings. The National Plan should specifically recommend inclusion of delivery system research on the national research agenda.



Given the rapid pace of scientific research and knowledge gained, tapping into the expertise from both the public and private sector on a regular, ongoing basis will be critically important to making significant progress by 2025. We applaud the National Plan's call for greater collaboration through Public-Private Partnerships as effective partnerships will play critically important roles in realizing progress in the prevention and treatment of AD, and urge that the final Plan include specific plans to engage public and private stakeholders on an ongoing, regular basis to further develop and implement the plan.

Public-private partnership efforts could prove particularly useful in the development, implementation, and updating of the national research agenda; clinical trial recruitment and development of patient registries; and the development of biomarkers for AD diagnosis and monitoring progression and developing clinical trial endpoints. Public-private partnerships can also enhance regulatory science efforts and informed review processes for potential new treatments by assuring that regulators and other decision-makers are up-to-date on the latest scientific understanding, research challenges, and progress made on AD. These partnerships also offer the opportunity to develop consensus-based best practice recommendations for every setting where people with AD are served to increase quality and efficiency. We recommend that the final National Plan specifically encourage greater public-private collaboration in these critical areas and regularly engage a wide variety of stakeholders including medical, clinical, and public health professionals, patients and family caregivers, community organizations, the biomedical research industry, public and private payors, long-term care providers, and employers.

We also commend the inclusion of efforts to facilitate the translation of research findings into medical practice and public health programs and to educate the public about the latest research findings. We recommend that the National Plan include recommendations that information be presented in ways and through vehicles that are both understandable and actionable to providers, public health professionals, payors, and the public.

### **Supporting Family and Friend Caregivers**

We commend the National Plan for recognizing the tremendous burden AD places on family and friend caregivers and the need to do more to support them, including educating healthcare providers on the need to evaluate caregivers for signs that their own health is at risk. Providers' ability to do that effectively, however, depends upon them being able to identify family and friend caregivers. Encouraging providers to document on medical records that a person is a family caregiver for someone with AD or another chronic condition would assist that outreach greatly. Likewise, the ability to facilitate better coordination of care, including care occurring outside medical facilities, would be enhanced if providers noted the name of the primary caregiver(s) on the AD patient's medical record. We recommend that the final National Plan include outreach to providers to incorporate such documentation into the medical records for both family caregivers and the people to whom they provide care.



Early detection and diagnosis of AD will help significantly with care planning and aligning support for the person diagnosed and his or her family. An additional step in early detection should be engaging the person with AD and family caregiver in advance care planning, so that the person with AD can have substantive input while they have the capacity to do so. We encourage the inclusion of this step in your recommendations. The National Plan includes efforts to educate providers, caregivers, and attorneys on AD, disease progression, and the costs associated with care. We suggest that educational efforts also include financial advisors, as the costs of care and long-term nature of the disease necessitate careful financial planning.

### **Assure Adequate Funding to Realize the Promise of the National Plan**

An excellent National Plan is only a set of great ideas without the funding to make them a reality. The Administration's recent announcement of additional funding for AD research and support for people with AD and their families represents a good start, but much more will be needed to implement the National Plan. One near-term opportunity is assuring better coordination of clinical care with community resources at the state and local level. States and communities should be supported to facilitate this coordination to streamline access to essential services for families and increase the efficiency of the systems at the state and local level. Many states are actively engaging public health resources to address the burden of AD. The National Plan should build on these efforts and those at the Centers for Disease Control to fully engage public health resources to evaluate the AD burden and work to address it. This suggestion is in concert with existing policy such as the Strategic Framework on Multiple Chronic Conditions.

When evaluating the need to devote resources to implementing the National Plan, we urge the Administration and congressional appropriators to consider the significant budgetary toll AD exacts. According to the Alzheimer's Association, AD will cost the United States more than \$200 Billion in 2012 with the trajectory increasing to more than \$307 Billion in just 15 years and almost \$1.1 Trillion by 2050. In times of tight budgets, we understand that finding the resources to implement the National Plan will be increasingly difficult, but given the tremendous toll AD takes not only on those afflicted and their families, but also state and federal budgets, these are investments we simply must make.

We applaud your efforts in the development of a National Plan to Address Alzheimer's Disease. The draft represents a well-considered, comprehensive approach. We appreciate the opportunity to review and comment on the draft Plan, and look forward to starting the hard work of implementing the final Plan to make a significant difference.



Sincerely,

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cc: National Advisory Council; Dr. Helen Lamont